



Self-care, adherence and uncertainty: biomedical treatments and patients' experiences regarding chronic migraine pain

Autocuidado, adherencia e incertidumbre: tratamientos biomédicos y experiencias de pacientes en el dolor crónico de la migraña

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ABSTRACT Based in the social sciences, this text explores and analyzes the particularities of migraine treatments using a relational approach, articulating the statements of professionals with the experiences and practices of patients in health services and their everyday care trajectories to manage pain. This qualitative research study utilized semi-structured interviews with neurologists and patients in a public hospital in the Autonomous City of Buenos Aires. A number of processes were observed by which biomedicine assigns part of the responsibility for the course of the disease to the patient through the logic of self-care. Patients must make changes in their ways of life in order to prevent headaches from appearing. Nevertheless, as the efficacy of these modifications is unclear, daily life is filled with uncertainty and charged with the mandate to follow care guidelines, which are valued not only professionally but also socially.

KEY WORDS Chronic Pain; Migraine Disorders; Therapeutics; Self Care; Uncertainty; Argentina.

RESUMEN En este escrito se exploran y analizan, desde las ciencias sociales, algunas particularidades de los tratamientos para la migraña desde un enfoque relacional que articula los dichos de los profesionales con las experiencias y prácticas de los pacientes en los servicios de salud y en sus trayectorias de cuidado cotidianas con este dolor. Se realizó una investigación cualitativa a través de entrevistas semiestructuradas a médicos neurólogos y pacientes en un hospital público de la Ciudad Autónoma de Buenos Aires. Se observan un conjunto de procesos por medio de los cuales la biomedicina delega en los pacientes parte de la responsabilidad del curso de su dolencia a través de una lógica de autocuidado. Los sujetos deben realizar numerosos cambios en sus modos de vida a fin de evitar la aparición de los dolores de cabeza. Sin embargo, al no existir certezas en torno a la eficacia de estas modificaciones, la cotidianidad se recubre de incertidumbre y de la exigencia de seguir pautas de cuidado cuyo cumplimiento es valorado no solo por los profesionales sino también socialmente.

PALABRAS CLAVES Dolor Crónico; Transtornos Migrañosos; Tratamiento; Autocuidado; Incertidumbre; Argentina.

INTRODUCTION

Temporary painful experiences, whether caused by an illness, an accident or any other circumstances, are considered to be “probable” and “normal” in a subject’s life (1). However, chronic pains cease to be temporary experiences, becoming a condition that changes the sense of suffering and of achieving some relief after a treatment. Several authors state that chronic pains (headaches, backaches, and others) mediate the social relationships of subjects and therefore it is necessary to investigate the meanings that those experiences acquire. Moreover, as medicine fails to treat these illnesses efficiently, chronic pains expose the contradictions in the medical perspective of treating suffering with rational and instrumental techniques (2). For example, professionals tend to associate chronicity with extension over time, leaving aside aspects related to the everyday life of their patients.

The transformations of contemporary capitalism, such as economic deregulation, the weakening of State functions, and precarious employment have not only increased exclusion and social heterogeneity (3) but also influenced the emergence and/or amplification of new ways of suffering. In other words, there are economic and political dimensions (local, national and international) that have dissolved modes of well-being, producing new bonds between well-being and the market and, therefore, new feelings of sickness and suffering (4).

Biomedicine looks for the causes of illness within the body, using objective and scientific knowledge to carry out a diagnosis and propose a treatment. Thus, the definition whereby biomedicine understands, diagnoses and treats certain aspects of chronic diseases that refer to the patients’ way of life can be explained (partially) as having positivism as an epistemological model. Bodies are the object of an attentive manipulation in which a “biological” body, different from the one we interact with in everyday life, is reconstructed (5).

This is the model that medicine has traditionally practiced and perpetuated, and it can be applied both to those diseases that biomedicine defines as “acute,” generally characterized by

causing organic damage or injury and with a treatment oriented towards curing, as well as chronic diseases such as diabetes, HIV, and hepatitis C. In both cases there is factual evidence of the disease. In other words, there are different indicators that prove, with the use of studies (tests, analyses, images), that something is out of the range of the “normal parameters” expected by medicine. However, chronic diseases, with diverse social meanings, differ from acute diseases in that they are characterized by long-term development, an uncertain course, development and healing process, intrusiveness, impact in patients’ lives and high cost (6).

On the other hand, there exists a group of chronic illnesses which, although they are diagnosed and treated by medicine, differ from both “acute” and chronic disease in that they show no “biological” evidence of their factual reality and their causal explanations. As a result, such explanations tend to be vague and fragmentary. Migraines are a good example of such chronic illnesses. They are a type of recurring headache for which there are no empirical indicators as to the reasons for their appearance. These headaches generally occur in one half of the head and are accompanied by nausea, vomiting, sensitivity and intolerance to light, sounds and smells. Other frequent symptoms include: joint pain, dizziness, a tingling sensation, and a particular sensation called an “aura,” which, according to patients, provokes visual alterations (flashing lights, rays of light, and others) and, occasionally, brief and temporary memory loss.

The professionals interviewed define migraine as a neurological disease, generally having an underlying genetic factor. They describe it as “a type of primary cephalalgia” (a), “a headache with specific characteristics,” “a neurological alteration,” among other explanations. These different ways of naming one type of pain show the biomedical difficulty in explaining an illness which does not correlate with what medicine has habitually understood as disease.

The characteristics and special features of the migraine not only come in to contradiction with biomedical knowledge but also with the findings of some studies from the social sciences that show that professionals discredit the statements of patients with chronic illnesses (2-7). Unlike with other

chronic pains, the migraine diagnosis is based in the legitimacy doctors give to their patients' narratives of their own physical and emotional experiences with headaches. In fact, due to the lack of other types of evidence, patients' experiences are not only listened to and acknowledged, but also incorporated and legitimized as fundamental parts of the biomedical definition of the illness. After biomedicine succeeds in eliminating any traits of subjectivity and transforms these accounts into neutral, objective and scientific categories, professionals use a combination of *biological* and *social* conditions to explain the occurrence of headaches. For example, being a woman and having a family member who also suffers from migraines are two factors that can predispose a person to the illness, as can eating specific foods, consuming alcohol or not engaging in physical activity (8).

Biomedical knowledge legitimizes the incorporation of social conditions as possible causes for headaches through the epidemiological notion of *lifestyle*. A "healthy life" is necessary in order to prevent future diseases and/or to improve existing conditions. Biomedicine conceptualizes the fulfillment of these social aspects with the notion of *adherence*. Professionals understand adherence as the level of commitment and the behaviors and attitudes of compliance patients have regarding the treatment (9).

This particular type of rationality and morality sets up a framework of values regarding certain actions and bodily manifestations (10). In other words, health becomes a central concept in modern identity which, by way of specific precepts, assigns moral values to the cultural order and influences in the creation of a self that can acquire positive values (if healthy) or negative values (given a health problem that places the person in a position of subordination and stigmatization). The link between health and morality resides in the idea that a "healthy" subject and a certain body image are associated not only to biological characteristics, but primarily to a responsible and respectable kind of person (11).

The impact of the biomedical field on daily life, which permeates different practices and activities, is analyzed by Foucault using the notion of medicalization (12). Conrad (13) furthers the study of this category and defines it as a process by which non-medical problems are referred to and

treated as diseases or disorders. Consequently, different aspects of daily life fall under the control, influence and supervision of biomedicine. According to Conrad, medicalization is the result of sociocultural processes; its crux resides in the fact that, after defining a problem in medical terms, biomedical language, frameworks and interventions are employed for its eventual diagnosis and treatment (13). Medicalization is a term considered in the social sciences to be critical of the scope and impact of biomedicine in different spheres of daily life (12-15).

As a result of the medicalization of spaces which were previously unrelated to medical knowledge, this text investigates and analyzes the logic of self-care (16) as a process that not only modifies the relationships between doctors and patients through care practices and strategies regarding the illness, but also increases the responsibility of patients in relation to their disease.

Health care professionals measure the compliance and results of treatments in terms of the commitment and adherence of the patients to certain care practices and changes in their lifestyles. They are considered active subjects embedded in a web of practices and knowledge affected by power mechanisms that regulate modes of self-care (12,17).

Daily life is colored by regulations, rules, laws, patterns, schedules, foods, some of which are permitted and others which are forbidden and harmful. Although nothing can guarantee that complying with the prescriptions over daily life will have a direct impact on decreasing headaches, non-compliance transforms the subjects into "*patients who don't adhere to and don't commit themselves to treatments,*" whose actions are socially sanctioned as "morally wrong."

RESEARCH AND METHODOLOGY

The research study adopted a qualitative methodology. The accounts of both professionals and patients (b) about certain characteristics of the migraine treatment process were described and analyzed. This approach allows direct contact with the actors' points of view through their own narratives and makes it possible to access

subjective and symbolic aspects of the population under study (18). The fieldwork was carried out in the neurology unit of a public hospital in the Autonomous City of Buenos Aires during 2010 and the first four months of 2011. Semi-structured interviews were conducted with 38 migraine patients (29 women and 9 men) from a middle/lower-middle socioeconomic class. All of them were between 21 and 60 years old.

Fifteen professionals from the same public hospital were interviewed (8 women and 7 men). The age range was 35 to 60 years of age among the female professionals and 34 to 70 years among the male professionals. Three of the doctors were neurologists specialized in migraine treatment, seven were neurologists with other orientations (specialists in Parkinson's disease, abnormal movements, general neurology), and the remaining five were resident doctors in their last year at the neurology service. In addition, two other neurologists from a private clinic (a 45 year-old woman and a 57 year-old man) were interviewed given their medical background in migraine treatment.

An interview guide, complemented and interspersed with spontaneous questions arising in the course of the interviews, was used with both doctors and patients. The design was oriented by a group of categories that have proven to be important in the study of other chronic illnesses according to previous studies. As fieldwork advanced, this system of categories was revised, extended and modified.

Grounded theory guided the development of theory based on the empirical data following a process of inductive analysis. The number of interviews and observations was determined by the criterion of data saturation, that is, the point in the investigation at which no new information was obtained with respect to the main categories, according to the theoretical relevance of data (19).

Analysis of the information

The interviews were coded and analyzed based on themed categories that guided the process of data analysis:

- *Patient interviews:* general living conditions, experiences regarding their illness, changes in

their everyday lives because of the illness, trajectories and characteristics regarding care practices for migraines.

- *Interviews with professionals:* characterization of the illness and diagnosis, therapeutic practices (types of treatment, forms of medical prevention and/or habits and behaviors that, according to the professionals, patients can adopt to decrease headache frequency).

The method of participant observation was also used in the waiting room and in case discussions with residents in the neurology unit. Firstly, it was possible to attend a series of case discussion sessions in which professionals specialized in migraines presented the features of this type of headache to the residents (different theories about its origin, necessary stages of consultation, forms of prevention, etcetera). Through these observations it was possible to observe the doubts and questions that the residents voiced to professionals about the diagnosis, as well as the medical characterization of the illness.

The waiting room for the patients seeking care for their migraines was shared with other patients that attended the hospital for other neurological problems. Informal conversations and comments about these diverse problems were recorded. On some occasions, it was possible to talk with patients that had been previously interviewed, who were attending the hospital for their treatment follow-up. These chats provided information regarding the changes and consequences brought by treatments, as well as different matters concerning the daily experience with headaches that were not mentioned in previous interviews.

Ethical safeguards

This investigation complied with the mandatory informed consent and confidentiality criteria required in health studies in order to guarantee the participants' rights as well as protect their identities. The patients interviewed were all over 18 years of age. To carry out this field work in the health service, the evaluation process required by the Ethics Committee of the hospital was carried out.

RESULTS

Care, adherence and uncertainty

So there is a genetic factor that biologically predisposes someone. As with everything in medicine, you have to add to that the environmental factors. I can have a genetic predisposition in my family for oncological problems, but my lifestyle can also make it so that the disease does or does not manifest itself. The same happens with migraines. If, apart from having family members with migraine problems, I don't get good sleep, I eat badly, I like to drink wine often and so on... my migraine attacks will be more and more frequent. (Neurologist)

Medical practice transforms illness into pathology, that is to say, into objective facts based on empirical evidence structured into the relevant biological field. Generally, a precise diagnosis, a treatment and, sometimes, a cure are obtained from these observations. This model of disease associated with organic damages and/or injuries promotes curing through treatments. Moreover, professionals construct sickness and the body as medical objects (5). These are discourses of a generalizing nature and with universal validity (20). In other words, the cure for certain diseases (especially those that medicine calls "acute") is achieved through standardized treatments, which are applied homogeneously regardless of the subjects who are suffering from the illness.

Nonetheless, the increase in chronic illnesses such as migraine, which do not respond to the current formalized etiological model, questions biomedical knowledge. For this reason, over time, a new type of logic was added to the curative logic mentioned previously, the goal of which is no longer to cure. These are treatments aimed at decreasing (or preventing from worsening) the symptoms of chronic illnesses.

According to the professionals' narratives, migraines do yet not have a cure. The goal of the treatments is to decrease the frequency and intensity of the headaches and other symptoms in order to improve the quality of life of the people who suffer from them.

The knowledge that no cure is possible – on the part of both doctors and patients – influences the subjects' narratives regarding their way of responding to pain and their perceptions about the illness and its treatments. For example, when a migraine sets in (suddenly and unexpectedly), a routine and a set of actions exist that include isolating oneself, turning off lights, and lying still, among others. At times a combination of feelings of resignation and habituation regarding treatments can be observed. As patients know that there is no cure, their expectations of a successful outcome decrease and their anxiety increases, because they are uncertain what to do to reduce the frequency and intensity of the pain. This awareness of the impossibility of a cure also affects the patients' trajectories in the health services and in their search for answers to their pain.

The techniques and procedures they seek out are varied and numerous and change according to the socioeconomic conditions of the patients and their historical context. At the same time, the disease's chronicity modifies the perception of pain as something external and strange. At intervals, and over time, it becomes something that patients say that they "learn to live with."

The factors involved in the development of certain diseases according to biomedical knowledge have become more complex in the last decades. There are psychosocial variables (systematized as *lifestyle* factors) that affect the development of illnesses and, therefore, need to be controlled through prevention and treatment (21). In this sense, through different theoretical perspectives, self-care (from the social sciences) and *lifestyles* (from biomedicine) refer to how patients, progressively, must take responsibility for the care of their illnesses through controlling and making changes in their ways of life.

In the narratives of the doctors, "*the pharmacological is combined with the non-pharmacological*," that is to say, medications are combined with changes in everyday practices and behaviors. Most of the neurologists interviewed say that *lifestyles* are a possible causal explanation for the origin of migraines, and an important factor to consider for preventing and, once the disease is present, treating the appearance of symptoms or headaches. This notion produces a vicious cycle whereby the patients must follow a set of rules and

are made responsible not only for the appearance of the symptoms, but also – in cases where no biological history exists (for example, family members with migraines) – for the success or failure of the treatments and the appearance of the disease.

When the professionals inform patients about the appropriate actions to prevent headaches, they are putting on them the responsibility to control and be aware of their own body and to change their practices and behaviors. The medical indications, cloaked in the concept of self-care, are experienced by patients as medical prescriptions that take the form of an order that follows a very different logic from their everyday life (16 p.91).

Self-care strategies show the ways in which medical practice no longer concentrates its power in the institution alone, but also exerts influence other spheres of life related to the patients' private and personal conditions. In other words, numerous practices and ways of life are systematized and incorporated as indicators that can improve, prevent, control or avoid certain illnesses.

As a result, the self-care complex allows for the exploration and analysis of how relationships between doctors and patients are influenced and affected by biomedicine's demands of commitment and adherence, demands by which subjects are made responsible for their suffering.

The processes of medicalization of everyday life (12) extend the medical scope to other contexts and permeate subject's activities and actions, thus modifying their relationships with themselves and with others. According to the professionals interviewed, complying with these guidelines is not an easy task; this is the reason why they have difficulties getting patients to give proper importance to their suffering and adhere to the treatment. They also acknowledged that *"a person with migraines can go ten years with that pain without ever looking for help"* (neurologist). Adherence is a medical category that implies an attitude of compliance or non-compliance with the treatments, depending on what patients do (or do not do) to improve their health. In this definition it is implicit that the patients' daily behaviors are evaluated from the professionals' point of view (9).

However, for the patients, *"taking care of the illness"* and complying with the treatments and medications prescribed by the professionals does not depend solely on knowing what the migraine

triggers are. There are social and economic conditions that have a great impact on the access to medications, health services, changes in eating habits, exercise, and so on. Moreover, in many cases patients stated that the pain returned even when they followed all the instructions that professionals had indicated to them.

Being healthy is in this way linked to moral issues, self-control and good behavior. It is a notion that has a symbolic power that creates and recreates the self in relation to a *"social self,"* in other words, a dominant morality that guides a set of rules regarding what is and is not accepted (21). By combining the narratives of both professionals and patients, it is possible to examine how the responsibility that doctors demand becomes at times an act of blaming the patients and making them responsible for their situation.

Comings and goings: on the continuity of treatments

Migraines are so common that most people don't respect them as a disease, not people in general and not even the patients. Because, for example, if someone has a finger that begins to turn black over one, two, three days, that person goes to the doctor right away. The same happens with chest pain. But we see people who have had headaches every day for ten years. "I had to get used to living like this," they say, they don't respect this type of pain. (Neurologist)

The wait or delay before consulting a health care professional regarding the headaches was mentioned by both doctors and patients. The health care professionals state that *"people don't respect the pain and that's why they wait so long, that doesn't happen with other diseases"* (Neurologist).

Most of the patients with migraine said they had had headaches for a number of years. Nonetheless, the reasons why they *"bear the pain"* do not coincide with the doctors' statements. In other words, the bodily technique of bearing pain does not only modify ways of feeling, modes of expression and social values, but also produces,

reproduces and responds to certain mandates and accusations of official and/or dominant discourses (4 p.232). People suffering from migraines say that one of the reasons why they have had to "grin and bear it" is related to the social characteristics attributed to headaches, associating them with excuses and lies. Thus, there are a number of discourses (biomedical, social) that influence and condition the fact that, in some illnesses and not in others, it is necessary to bear the pain.

In some cases, patients say *"I went from one neurologist to another, but found no solution; so I decided to stop going, because it was always the same story: they'd do an EEG and the results were fine..."* (Susana, 39 years old)

I'll tell you, after doing lots of treatments, I really didn't want to come here, because it's kind of disappointing... It took me a while to come, because I didn't want to go to a doctor and have it not work out, and then to another one and have it not work out again, and after that to a third one. Of course you want to find a solution, but you're a bit disappointed, because the medications even cause side effects, like gaining a lot of weight, and I never lost those pounds. So, I put a lot of effort into it but I kept having headaches. (Eric, 47 years old)

Patients say that, before visiting their current neurologist, they had a trajectory with different professionals, marked by disappointment with treatments that never worked. Others said that they had been living with the headaches for years, but added: *"why see a doctor, if headaches are so common?"* (Lucía, 35 years old). From what patients say about their perceptions of their environment, it can be inferred that it is problem considered common and frequent, because *"there are more important things to go to the doctor for, right?"* (Lucía, 35 years old).

There are multiple and varied reasons for delaying medical consultation. The social and economic conditions of the patients are a crucial aspect. First, regarding the consult, it is necessary to have access to the information about whether in a certain health service there is a department specialized in migraine treatment. Secondly, people also need to have the time to go to the consult, for example, on a weekday morning. And even

if it is possible to access and begin a treatment, the majority of the patients said that the cost of the medications prescribed by the professionals was an obstacle, as most of these medications are imported.

With my budget it's a little complicated. They don't cost five hundred pesos, but... seventy, eighty and, if I don't have prescription forms from the healthcare company, which I sometimes do... I have to pay the full price without a discount. She prescribes me Ketorolac to take as soon as the pain sets in, which is quite expensive, so I asked her if I could take Ibuprofen instead, because it's cheaper, and she said that was ok. (Mirtha, 41 years old)

The economic problems to buy the medications that Mirtha described are frequently commented by the other subjects interviewed and show the obstacles that some patients face in sustaining the treatments over time. Another reason that can cause the delay in the consultation or non-adherence to the treatments is the generalized assumption (shared by both doctors and patients) that the effectiveness of migraine treatments is very limited. In the words of one of the professionals: *"Migraines have a biological origin, but the gene involved in the disease has not yet been isolated"* (Neurologist). There are so many conditions that patients need to bear in mind to avoid headaches that it is worth asking: What are the chances that someone suffering from migraines could comply with all of the requirements proposed by biomedical knowledge (eating habits, exercise, hours of sleep, family history, etcetera)?

The problem is that a couple of times I've made the mistake of stopping the treatment. Because, as I said, I didn't want to take a lot of pills. And the doctor tells me that if we try to follow a treatment and I stop it, it's more difficult to reduce the dose. Because, last year I felt good and so I went ahead and said: ok, I'll stop taking the pill. The doctor tells me that if I follow the treatment correctly, we can keep lowering the dose and eventually I won't need to take it anymore. (María, 26 years old)

Like María, others said:

...I come back when I feel worse, but if I see some improvement, I stop coming for a while.
(Lautaro, 30 years old)

...when I get tired of the headaches, I consult a doctor. (Bárbara, 27 years old)

Although this text focuses on the relationships and tensions between professionals and patients through the analysis of the characteristics of migraine treatments, it was possible to use the words of the patients to identify different perceptions and strategies of care which are alternative or complementary to the biomedical treatments.

The patients' search for alternative treatments for migraine was varied and differed in each case. In some cases, they mentioned that although they had not tried other types of medicine:

...I would like to, because holistic medicine uses a minimum of medication and is more natural. (Edgardo, 38 years old)

...actually, I didn't. But I'd like to try... one of the elderly ladies I work with told me she used to take a few drops of a tincture every morning... I don't know what they were for... she tells me, why don't you see another doctor? (Julia, 58 years old)

Additionally, there are patients who tried other options and shared their experiences with different treatments (homeopathy, acupuncture, and others):

...I consulted a homeopath for about two years, but it didn't work... then I tried acupuncture... for two and a half years, but it didn't work either because I stopped taking Migral. I don't like to mix treatments. (Silvia, 47 years old)

Furthermore, patients frequently make reference to a combination of treatments prescribed by the professionals and those the "doctors don't agree with very much." This type of strategy includes therapy, medicinal herbs, teas, among others:

I've tried almost everything, because I have a friend who also has cephalalgia, and so we always take medicinal herbs... like, linden tea, chamomile tea... but doctors really don't like that very much. (Patricia, 26 years old)

I even saw an Umbanda priest, and I remember he told me to bow and he washed my head with beer... never again... and then I went to those people who use cards to foretell the future, to the Universal Church of the Kingdom of God... everywhere you can imagine. And when people say "it's lack of intelligence that drives people to those places," I say that it's the desperation of not knowing what to do. (Mirtha, 54 years old)

This possibility of coming and going with treatments without the fear of getting worse or dying is related to a particular characteristic of migraines, that a professional defined with these words: "migraines have something good and something bad: the bad thing is that they can't be cured and the good thing is that the headaches won't kill you" (Neurologist).

Most doctors agree that pharmacological treatments may not work and it may be necessary to switch medications. Nonetheless, they do not doubt that lifestyle changes, that is, the modifications in the patients' habits and actions, are an essential element to preventing headaches from appearing.

Chronicity, commitment and self-care

This is not the magic pill the patient comes looking for. Commitment is crucial.
(Neurologist)

In recent years, the increase in chronic pains has changed the way biomedical practice names and treats certain diseases. Multiple conditions can exist that interpose and affect such illnesses. Instead of talking about curing, doctors make reference to "processes," "maintenance," "care."

Pharmacological treatments consist of medications prescribed by professionals. There are two types of medications. One type is preventive medication, which "is generally used in migraines;

you prescribe a medication to avoid the recurrence of the headache and the patient has to take it every day" (Neurologist). The other type is what professionals define as attack, rescue or *abortive medication*, taken as soon as the headaches set in: *"the abortive type of medication is the one we all use, when I have a headache I take an analgesic"* (Neurologist).

Nonetheless, as was mentioned earlier, professionals ascribe a central role to the patients' actions and practices, both in the theories about the causes of the migraine and in the explanations of prevention methods. Doctors repeatedly stated that *"medication is not enough, because the migraine patient is very sensitive and needs to go to bed at the same time every day, eat regularly, drink a lot of water, and exercise"* (neurologist). However, at the same time, doctors rarely mention the problems and difficulties that could arise and lead to the interruption of the treatments, such as the lack of time, money, and information regarding access to medical consultations, complications with eating certain foods, and so on. Therapeutic practices are transformed into daily activities and changes for the rest of the patients' lives, ignoring the conditions which make it possible for different ways of dealing with the same illness to exist.

They're like preventive measures to avoid pain from setting in; but really they are everyday habits. For migraine we advise patients to do relaxation exercises, tai chi, yoga, Pilates, now that that's popular. We recommend that they avoid fasting, that is to say, to eat regularly and in an organized way, to sleep well at night (seven or eight hours a day minimum), to stay properly hydrated, to avoid coffee, if possible. We can tell them to avoid tobacco, too. And then there are a series of hygienic and dietetic measures which are described, but doctors regulate those according to what the patient says. (Neurologist)

Chronicity introduces a new way of treating illnesses, which combines and complements the *pharmacological* with *hygienic and dietetic measures* (for example, avoiding excess weight, sleep deprivation, a sedentary lifestyle, lack of exercise

and "learning" to control the causes that trigger pain, which differ from patient to patient).

Although the self-care logic seems to give patients more autonomy because it extends the spaces of decision regarding the illness, at the same time, if the pain continues it is a logic that makes them responsible for their situation. In other words, if the migraine maintains the same frequency and intensity it had before the treatments, there are different theories that, depending on the actors, explain why the headaches persist.

The professionals propose a patient that, from a rational and individualistic perspective, chooses to follow certain guidelines for improving his or her medical condition. At the same time, they make reference to the patients' lack of compliance regarding their treatments. They say that *"migraine patients don't adhere to their treatments like they do with other illnesses. It's cyclic, when they improve, they stop coming; when the pain returns, they come back."* (Neurologist)

I think that we need to make patients understand that they need to commit. And that is one of the most difficult things to accomplish. The care provided to the chronic pain patient has to do with commitment, involvement and acceptance [...] To say, ok: "It is you who has the responsibility, not the doctors." And it's hard to make patients understand this. That's why they go from one doctor to another, looking for some magical solution, when all the doctors do is give them a different pill. That's also why adherence to the treatment is so erratic. Generally, patients don't adhere to the treatment as well as they do with other neurological diseases. (Neurologist)

The biomedical category of *adherence* is built on the basis of a normative model, that is to say, of "what ought to be," which is characterized by a deep patient responsibility towards the illness and its resolution. Therefore, a discursive typology is proposed which classifies patients as good and bad, patients who adhere or potentially adhere and patients who do not adhere (9 p.289). However, the study of chronic illnesses should move beyond the idea of a person who does not commit or does not adhere and investigate the relationships between the pain and personal experiences and

trajectories (together with the social meanings attributed to headaches).

It's that it's easier for people to do the things that imply the least commitment. To walk, to get off the bus before your stop... I don't know, to organize yourself better with your food, to eat better... If you attack that, which is cheaper, let's say, you're going to have better results, you'll feel less pain. Put that's much more sacrificed, in a sense. Because it requires you to... It puts the ball in your court, you know? It's more comfortable for you if the doctor simply gives you something... solves the problem for you. The problem really begins when you realize that the ball is in your court and you have to maneuver it yourself. That's the point. (Neurologist)

For most interviewed professionals, adherence is a fundamental attitude and behavior in the process of dealing with the disease, and it goes beyond biomedicine, extending into other spheres of everyday life for indefinite periods of time (22). Adherence is about changes in the patients' lifestyles, which include "being patient and not rushing to put on the roof before you build the walls" (Neurologist).

In the treatment, not only do patients need to have a discipline and control that will help them reduce their headaches, but also, this compliance will allow them to obtain a morally acceptable social image in which others recognize the commitment, concern and interest they have for their health.

Knowledge, responsibility and uncertainty

I see what I can do to avoid the headaches. I do what the doctors say, drink a lot of water to avoid the pain; when I gave up smoking the strong migraines became less frequent. Ah... stress, not sleeping well, not eating regularly, those things will definitely give me a migraine in the afternoon. So, I need to have a certain order, an organized life if I want my day to end well. (Carla, 38 years old)

The biomedical process of recovering and legitimizing what patients share about the characteristics of their headaches forms part of a logic that allows professionals to provide answers to diseases that do not share the characteristics of their epistemological model. Doctors group together a set of heterogeneous accounts of symptoms and sensations and transform them into a delimited and recognizable illness.

Doctors also ask patients to keep a migraine diary in order to understand their lifestyles. Patients keep track of the number of headaches they have between appointments, the times of the day the headaches occur and the situations connected with the appearance of the headaches. Professionals consider these accounts to be

...a record of their daily life. The most basic things they should ask themselves are: what food they eat, the number of hours they sleep, whether or not they get exercise, etcetera. In this way it is possible to detect and exclude what is causing the migraine. (Neurologist)

These are types of care, practices, and strategies that patients with migraines should carry out in order to uncover what may be causing the headaches and to prevent them from occurring. They may work in some cases and may not in others. That is why the knowledge about possible ways of taking care of oneself and living with the illness is fragmentary.

Different authors from the point of view of social sciences point out how difficult it is for chronic patients to get biomedical professionals to "believe" their pain is real. According to this perspective, biomedicine considers the patient's complaint significant only if it reflects a physiological state; if no empirical evidence is present, the whole meaning of the complaint is questioned (5 p.35). Nonetheless, the chronic pain of migraine contradicts these assumptions and shows the relevance and importance of the accounts of patients to professionals in the biomedical construction of the disease:

I do what I can within my possibilities. You have an illness that forces you to follow a strict diet, you can't eat this or that, you have to sleep eight hours a day and whatever

else... it's not possible [...] I live for the migraine, because a patient affected by migraine has to be very responsible in that sense. It's a very rigid routine and you have to put energy into it, because for example, you're tired, you come home from work and want to spend some time with your family, but no, you have to go swimming, because if you don't, you get a migraine. (Edgardo, 38 years old).

Edgardo's affirmation *"I live for the migraine"* clearly expresses and summarizes how invasive migraines can be in everyday life. "Living for" implies a high level of uncertainty (if some certainties about the appearance of pain and its relief existed, the possibility of "relaxing" would increase). This also means living with the fear that pain could set in at any time, of not knowing what to do to prevent it and the impossibility of complying with all the medical instructions about "lifestyle" changes (foods, exercise, hours of sleep, stress, etc.). And at the same time, those who fail to comply with these prescriptions tend to be considered patients that do not commit, that do not care about their own wellbeing.

Self-control, as the keystone for therapeutic action and achieving normality, implies an opposite and non-explicit alternative: lack of control, referred to as an attitude of the subject regarding his or her lifestyle characterized by the absence of modification of one's behavior (15). Thus, self-care becomes a system of care-control of oneself, where the subject adopts a permanent surveillance over certain aspects of his or her body and way of life which contradict previous ways of building experience (16). In the case of migraine suffering, the concern for avoiding irregularities and disorders in daily life transforms subjects into people who are attentive and concerned about matters which are apparently trivial (to those who do not have headaches) and which affect and modify their relationships and daily interactions.

FINAL THOUGHTS

In today's societies, "healthy" subjects are not only those with absence of disease, but also with a healthy and balanced life. This healthy self

is additionally sustained by the creation of a category of "unhealthy others" defined or imagined as those embodying the qualities outside of what one should do to be healthy (11).

These demands placed upon contemporary subjects seem to come into contradiction with chronic illnesses such as migraine. Firstly, it is a pain that recurs over time, that is of uncertain duration and that changes the everyday life of those who suffer from it. In addition, migraines present certain characteristics (in terms of their occurrence and the types of care) that, in the present work, allowed us to examine and analyze the relationships (and tensions) between health professionals and patients. The explanations of the reasons the pain appears and the different ways to treat it lie, mainly, in a set of social indicators that define the patients' *lifestyles*. Thus, in order to prevent and treat headaches, professionals include, as an essential part of the treatments, significant changes in the patient's way of life which deeply affect their corporal and emotional experiences. In this way patients learn to heighten their attention and concern regarding certain events and situations which seem insignificant to those who do not suffer from migraines but, in their case, could trigger headaches.

The boundaries between healthy and unhealthy activities are transformed into boundaries between patients who are concerned about their health and patients who are not. Although medical diagnoses and treatments generally have rational foundations, in the case of migraine, the methods to assess and treat the illness include social, moral and cultural matters that transcend the biological description of the body. This is an illness that goes beyond the organic and includes moral categories that confront patients with a particular diet, a concern for personal care and hygiene, and so on.

Self-care, as discipline and self-control, has become a predominant model of care for the body. Based on this model, a healthy body represents morality, responsibility and well-being (central dimensions of identity in dominant societies) (23). A person who cares about his or her health and follows healthy practices is socially esteemed and valued. On the other hand, when headaches persist, the patient becomes responsible for that situation due to his or her lack of adherence and commitment to the biomedical treatment.

What is paradoxical about this type of headaches is that the self-care practices involve countless changes that produce in the patients the feeling that *"there is always something that gets past me."* Their accounts about living with the pain and their treatment trajectories abound with expressions such as: "uncertainty," "anxiety," "lack of certainties," "failure."

Although professionals acknowledged the lack of certainties or guarantees as to the effectiveness of certain treatments to reduce the occurrence of migraines, they also pointed out that, in order to achieve improvements and a "good evolution of the treatment," patients should be: "committed," "responsible" "compliant with the treatment" and, above all, "organized."

You try to lead a peaceful life, as much as possible, but there is no guarantee of anything. At one point I looked for certainties in the treatment, but you have to get used to it, there are no certainties. (Eduardo, 38 years old)

I'll be honest with you; I used to think that alcohol was the cause of my migraine, so I gave it up completely in order to live better. But, the worst thing is when you aren't in pain and you worry that something could set it off and bring on a headache... because, as the doctor said and I agree, some things happen for no reason. (Eric, 47 years old)

Both Eric and Eduardo agree on the impossibility of certainties about migraines. Everyday life becomes a minefield of potential triggers for the pain that needs to be watched and guarded. While the most obvious medicalization process implies a concentration of power and knowledge in the medical institution, the self-care complex implies a decentralization from the institution and a multiplication of the nodes and focal points of the medicalizing network. Both the body and social relationships are at the center of a normalizing gaze which observes, assesses and compares in the terms of the ideal patterns upheld by the predominant scientific knowledge, leaving no place free from invasion and contamination by the "disease" (16 p.93).

ENDNOTES

a. The notion of cephalalgia is used repeatedly by the professionals interviewed to refer to migraines and means, according to a neurologist, *"a feeling of cranial pain, it's the technical name, the umbrella term. Within cephalalgia, there are primary and secondary types. The primary ones are those that don't show alterations in the tests. The secondary ones are related to a situation in which you treat the problem that caused the pain and the*

pain is resolved. Within primary cephalalgia is the migraine, which comes from the word hemikrania meaning 'half of the head,' because the pain is felt on one half of the head."

b. Although in the present work the notion of subject is defined, given that the investigation was carried out in a hospital, the words patient and subject will be used indistinctively.

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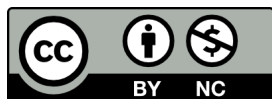
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